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Psychological factors that determine people's willingness-to-share genetic data for research

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Abstract

Of all the information that we share, health and genetic data might be among the most valuable for researchers. As data are handled as particularly sensitive information, a number of pressing issues regarding people's preferences and privacy concerns are raised. The goal of the present study was to contribute to an understanding of people's reported willingness-to-share genetic data for science (WTS). For this, predictive psychological factors (eg, risk and benefit perceptions, trust, knowledge) were investigated in an online survey (N = 416). Overall, participants seemed willing to provide their genetic data for research. Participants who perceived more benefits associated with data sharing were particularly willing to share their data for research (β = .29), while risk perceptions were less influential (β = −.14). As participants with higher knowledge of the potential uses of genetic data for research perceived more benefits (β = .20), WTS can likely be improved by providing people with information regarding the usefulness of genetic data for research. In addition to knowledge and perceptions, trust in data recipients increased people's willingness-to-share directly (β = .24). Especially in the sensitive area of genetic data, future research should strive to understand people's shifting perceptions and preferences.

KEYWORDS

risk perception, privacy, data sharing, genetic literacy, trust

1 | INTRODUCTION

Recently, research interest in health and medical information actively shared by people for the purpose of research has grown due to its potential for improving public health.[1-5] Health and medical data of interest range from people's lifestyle and nutritional choices, blood group and BMI, and medical history to their genetic data. Particularly, genetic data are considered sensitive information, which raises a number of pressing issues regarding people's preferences and privacy concerns.[6-8] The information gained from genetic data, such as someone's likelihood of getting Alzheimer, could be willingly or unwillingly be passed on to third parties, which in turn could process these data and link it with other personal data (eg, health insurance number, social security number). This in turn might have negative consequences for the individual who shared the information, for instance, to support medical research. Privacy is therefore a crucial topic when discussing people's willingness-to-share.

Up to date, experimental research into individuals' privacy preferences has largely been focused on voluntary sharing on social media or in business contexts.[9,10] The research basis into people's preferences regarding the sharing of health data for research is currently largely of qualitative nature.[11-14] An exception is a large-scale experimental study that investigated people's hypothetical willingness to give broad consent to biobanks.[15] The authors found that 66% of participants would be willing to give their consent and that the majority would want to be informed of the consequences

of data misuse. However, little is understood so far regarding the mechanisms that promote or reduce people's willingness-to-share genetic data. Thus, this study aims at investigating sociodemographic and psychological factors that will contribute to people's willingness to share their health and genetic data. This study does so by considering well-established concepts of psychological and risk perception research.

Risk and benefit perceptions are proximal predictive variables for the acceptance and, thus, the success of a product or technology.[16-21] According to previous qualitative research, people associated a variety of personal and public benefits with the sharing of genetic data and also had concerns regarding privacy and credibility.[22-24] Thus, for stakeholders (ie, researchers interested in analysing crowdsourced data, platform providers for data collection), it is important to understand lay-people's risk and benefit perceptions of data sharing, as this provides them with the tools to promote informed data sharing among interested lay-people.[25]

However, in order to perceive risks or benefits, potential data sharers need to be aware of the uses of health and genetic data in medical research and have some knowledge about privacy-related issues.[26,27] Boerwinkel et al[28] distinguished between different types of genetic literacy, such as conceptual knowledge (eg, knowledge of genetic concepts), sociocultural knowledge (ie, knowledge of applications of genetic technologies) and epistemic knowledge (ie, knowledge of meaning of genetic information). Particularly, knowledge about the uses of genetic data for research and privacy issues might have implications for people's risk and benefit perceptions and ultimately their WTS.[28-30] However, the impact of different types of knowledge has not been investigated systematically regarding people's perceptions of the sharing of their genetic data. A large body of evidence from other areas of research suggested that the imbalance in knowledge between experts or stakeholders and consumers might lead to different conclusions regarding risk perception, benefit perception, acceptance and behaviour.[31-34] For some potentially beneficial innovations, knowledge provision had proved successful to reduce risk perception and improve acceptability.[35,36] However, innovative technologies and applications are not necessarily judged by weighing the risks and benefits and considering objective facts by either experts or lay-people.[37] Frequently, risk judgements and decisions are influenced by previous experiences, effects or other readily available factors to reduce cognitive load.[37]

When people lack information about a hazard, they may rely on trust to assess the risks and benefits associated with the hazard.[19] Data sharing and privacy is an area where lay-people lack knowledge, as most people are unaware of the extent of data collection, how these data could be analysed and used and what beneficial or detrimental effects might arise for the individual.[9] In the case of data sharing, incomplete or asymmetric information, intangible risks with complex mitigation processes and benefit trade-offs lead to a heavy reliance on heuristics or other choice strategies that utilize information that people actually have.[9,38] One such information might be the trust that decision-makers place in the person or institution that receives the data.[39,40] In their systematic review, Clayton et al[41] identified the primary data recipient (and potential third-party recipients) as one of the major concerns that determine willingness-to-share genomic data. In the case of sharing health data for research, the trust that needs to be placed in the recipient of the data is of a transactional nature. The person sharing the data needs to have confidence in the abilities of the data recipient to keep the data safe. Additionally, the data sharer needs to trust that the data recipient uses the data for the intended purpose now and in the future (ie, researchers develop new ways to diagnose or treat illnesses and thus improve public health), instead of for ulterior purposes that do not match the data sharer's values (ie, researchers use findings to develop expensive new medications). Studies suggest that university researchers are trusted more than researchers from pharmaceutical firms, as the latter are assumed to have financial interests.[39,41,42]

2 | RESEARCH QUESTIONS AND HYPOTHESIS

The overall objective of this study was to offer insights into people's knowledge, perceptions and preferences regarding the sharing of their genetic data. Based on the hypothesis that people's decision to share their genetic data for science is comparable to other decision-making processes, a working model originating from previous psychological and risk perception research is suggested.[16,19] This model comprises people's knowledge, perceived risks and benefits, and trust in data recipient, as suggested by previous literature into people's privacy decision-making.[9] Specifically, the working model presented in Figure 1 will be tested. Subsequently, the included hypotheses are presented in more detail:

Risk and benefit perceptions are considered proximal to people's acceptance and involvement in innovative technologies.[16,17,21] Thus, the following two hypotheses were formulated:

- H1.1 Perceived risks (eg, privacy infringements) are negatively associated with willingness-to-share genetic data for research and innovation.
- H1.2 Perceived benefits (eg, improvement of medical treatments) are positively associated with willingness-to-share genetic data for research and innovation.

Risk and benefit perceptions in turn are influenced by the amount of information a person has received and, thus, the knowledge that this person has of an innovative technology.[26,28] It is likely that different types of knowledge impact either risk or benefit perceptions, as two types of data have been identified as the most relevant to potential data sharers[11,12]:

- H2.1 Knowledge about the use of genetic data in research is positively associated with benefit perception.
- H2.2 Knowledge about privacy aspects is negatively associated with risk perception.

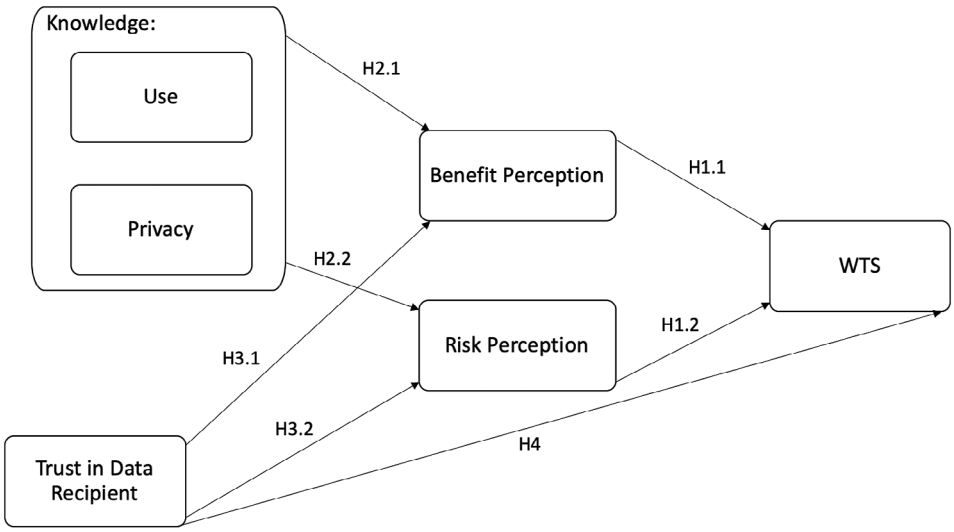

FIGURE 1 Suggested model and graphical representation of hypotheses H1.1 to H4

Finally, due to the novelty of the decision task of data sharing for research, people's knowledge might be scarce. Based on previous research,[39,41] it is likely that in such a situation the trust in the data recipient has an impact on risk and benefit perceptions and on willingness-to-share.

- H3.1 Trust in the data recipient is negatively associated with risk perception (ie, trust that recipients have the ability and willingness to keep the data safe).
- H3.2 Trust in data recipient is positively associated with benefit perception (ie, trust that the research will lead to medical improvements).
- H4 Trust in the data recipient will also directly increase willingness-to-share.

3 | METHODS

3.1 | Methods and materials

The sample was recruited with the support of a professional provider of consumer panels (respondi; Koeln, Germany). The panel members are recruited by respondi via online banners, Google ads, own market research projects and flyers. Quota sampling based on age and gender was conducted. The sample size was based on an a priori power analysis (α = .05, β = .80, medium effect). Participants were incentivised by the professional provider of consumer panels. For this study, participants from the German-speaking part of Switzerland were invited to participate. Previous research shows that awareness for the value of health and medical data for research is low among lay-people.[27,28,30] Therefore, at the beginning of the online questionnaire, participants were introduced to the topic with the subsequent section:

> Swiss citizens will soon be able to store their health and medical data (eg, nutritional behaviour and physical activity, medicines taken, blood values, genetic data) in an electronic collection. This would enable health-related information to be collected in a private data account and quickly accessed. The data in this account are encrypted and only the individual has the key. In addition, the person concerned can decide for himself whether and with whom to share which data. Of course, the data collection in the electronic collection is voluntary.
>
> There is great interest in medical research in these health and medical data, especially genetic data. The rapid advances in medical diagnostics and the development of information technologies mean that these data

TABLE 1 Sociodemographics of the sample (N = 416)

	Total	Female (*n* = 213)	Male (*n* = 203)
Age, *M* (SD)	45.4 (14.2)	44.8 (14.4)	45.9 (13.9)
Perceived health,[a] *M* (SD)	5.3 (1.1)	5.3 (1.1)	5.3 (1.2)
Digital affinity,[b] *M* (SD)	4.9 (1.5)	4.7 (1.5)	5.0 (1.6)
Education, N (%)			
Low education	30 (7.3%)	19 (8.9%)	11 (5.5%)
Medium education	204 (49.0%)	116 (54.4%)	88 (43.3%)
High education	182 (43.7)	78 (36.6%)	104 (51.3%)
Previous experiences with genetic tests, N (%)			
Yes	21 (5.0%)	9 (4.2%)	12 (5.9%)
No	395 (95.0%)	204 (95.8%)	191 (94.1%)
Chronic disease, N (%)			
Yes	110 (26.4%)	63 (29.6%)	47 (23.2%)
No	306 (73.6%)	150 (70.4%)	156 (76.8%)

[a]Range: 1 "no experience at all (=do not use it, no knowledge at all)" to 7 "a lot of experience (=use it frequently, expert knowledge)."
[b]Range was 1 "very bad" to 7 "very good."

TABLE 2 Included multi-item scales (N = 416)

	M	SD
WTS (1: not likely to share at all—7: very likely to share, α = .87)	4.09	1.93
Please indicate how likely it is that you would share the following genetic data. Please imagine that you have collected the data in question and stored it in your electronic depository		
…the examination of your genes for predispositions that could trigger certain diseases in your descendants (eg, cystic fibrosis, Tay-Sachs disease)	4.14	2.17
…information about your risk of getting a certain disease in the future (eg, Alzheimer, Parkinson)	4.13	2.15
…the correspondence between genetically predicted and actual characteristics (eg, eye or hair colour, blood group, taste preferences)	4.01	2.20
Risk perception (1: highly unlikely—7: highly likely, α = .88)	4.58	1.48
The data are passed on to unauthorized third-parties (eg, [health] insurance company)	4.81	1.82
The data are used to develop new, expensive drugs	4.64	1.73
The anonymization of the data cannot be guaranteed and you may be personally identified	4.58	1.81
The data are not kept secure and is accessible to third parties	4.54	1.83
The research findings are not used for the stated purpose	4.35	1.80
Benefit perception (1: highly unlikely—7: highly likely, α = .94)	5.08	1.49
The data are used to improve the diagnosis and treatment of common diseases (eg, cancer, cardiovascular diseases)	5.23	1.61
The data are used to advance medical research	5.20	1.65
The data are used to find new treatment options for a variety of diseases	5.17	1.63
The data are used to improve the prediction of genetic predispositions to disease	5.04	1.64
The data are used to improve public health	4.75	1.71
Trust (1: do not agree at all—7: agree completely, α = .94)	4.73	1.55
I trust university researchers that my health and medical data are used for the right reasons	4.78	1.63
I trust university researchers that all necessary measures are taken to protect my health and medical data	4.76	1.66
I trust university researchers regarding the warranted anonymity of my data	4.66	1.61

can be increasingly analysed and used to improve the diagnosis and treatment of diseases.

The participants were asked to imagine that university researchers would like to receive their data to analyse them for research purposes, including a sentence ensuring that the data will be stored and analysed independently of the personal data. The main variable of interest, *Willingness to Share Genetic Data for Research* (subsequently called WTS), was measured directly after this introduction with three individual items. Participants' *Risk and Benefit Perceptions* were measured with five items each. *Trust* was measured with three items compared with items by Siegrist et al.[19] Table 2 presents an overview of all included multi-item scales, as well as descriptives for the items and scales. Furthermore, two different types of *Knowledge* were measured: four items focusing on knowledge about the use of genetic data and three items measuring knowledge about privacy aspects of genetic data sharing. For the knowledge items, correct responses were coded with 1 and then summed up over all items of a scale. Figure 2 presents the distributions of the items included in the knowledge scales. The willingness-to-share items were formulated and checked by experts for accuracy and relevancy. The phrasing of the perception and trust scales was based on previous studies on people's perceptions of innovative technologies, but heavily adapted for the current context.[16,19] The knowledge items were inspired and partly adapted from previous literature on genetic literacy and also checked by experts.[27,43]

In the last section, participants' perceived health, digital affinity, previous experiences with genetic tests and whether they suffered from a chronic disease were assessed.

3.2 | Data analysis

All continuous multi-item scales were subjected to a principal component analysis (PCA, varimax rotation) and reliability analysis (Cronbach's α). All descriptive data analyses, repeated-measures analysis of variance, *t* tests, and bivariate correlations (Pearson product-moment correlation) were conducted in SPSS 25.[44] The path analysis with maximum likelihood estimation was conducted in Amos, and the acceptable model fit is suggested by CFI > .90, TLI > .90 and RMSEA < .05.[45]

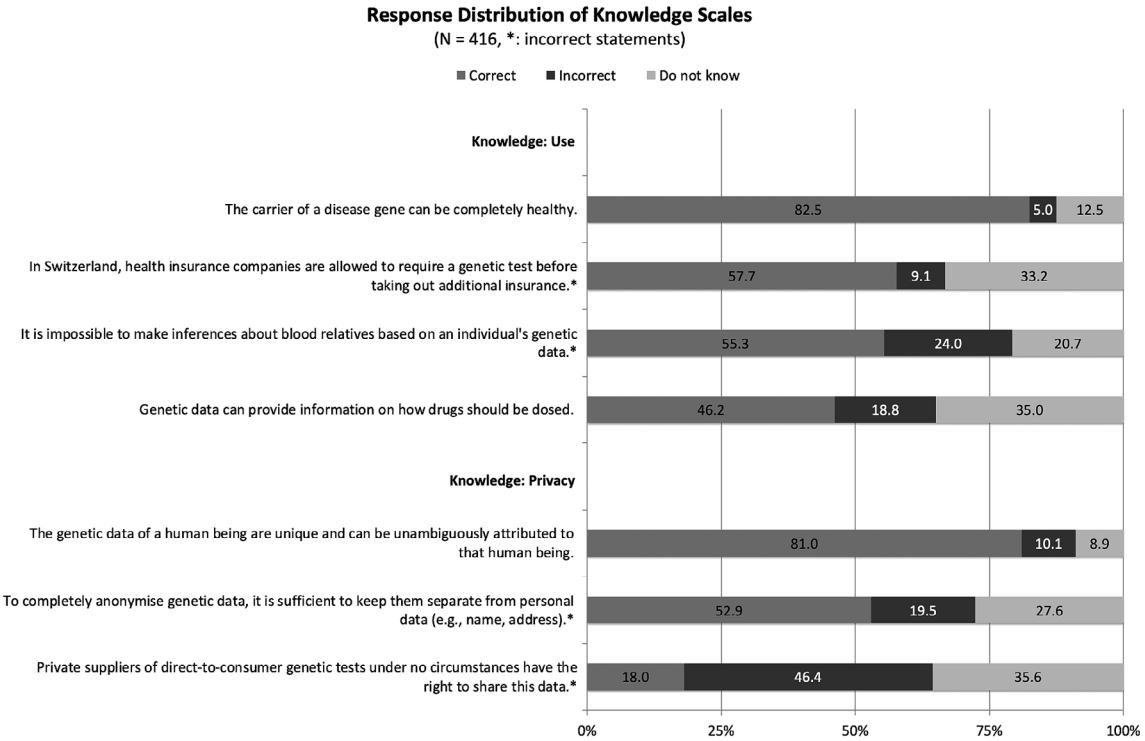

FIGURE 2 Distribution of the knowledge items (*incorrect items are indicated by an asterisk)

4 | RESULTS

4.1 | Sample

Of the N = 548 participants that clicked on the invitations link (100%), n = 95 did not progress further than the starting page and n = 41 dropped out during the course of the questionnaire. This corresponds to a participation rate of 82.7%. For the final sample, participants who took too little time for the online questionnaire were also excluded (n = 37). For this, the cut-off point was a duration of the median divided by two (184.5 seconds) as recommended in the literature.[46] Thus, the final sample comprised N = 416 participants (n = 213 female, 51.2%) with a mean age of M = 45.4 (SD = 14.2, range: 18-69). Education was recoded to ensure comparability with educational systems in other countries. Table 1 presents an overview of the sociodemographics of the total sample and separated by gender.

4.2 | Descriptive and scale analyses for WTS, risk and benefit perception, trust and knowledge

Table 2 presents the descriptives of the included multi-item scales, WTS, risk and benefit perception, and trust. Participants' WTS did not differ significantly for the three different types of genetic data: F (2, 830) = 1.5, P = .221, and η^2 = .00. The multi-item scales for WTS, risk and benefit perception, and trust were subjected to principal component and reliability analyses. All PCA resulted in one-factor solutions: WTS (eigenvalue: 2.4, explained variance: 79.2%), risk perception (eigenvalue: 3.4, explained variance: 68.2%), benefit perception (eigenvalue: 4.1, explained variance: 81.5%), and trust (eigenvalue: 2.7, explained variance: 90.0%). All reliability analyses resulted in good to very good Cronbach's α values for all four scales, with α = .87 for WTS, α = .94 for benefit perception, α = .88 for risk perception, and α = .94 for trust.

Figure 2 presents the distributions of the knowledge items. For all included items, participants' knowledge was rather low (do not know responses between 8.9% and 35.6%). The highest incorrect response rate, almost half of the participants, was observed for the item regarding the ability of private suppliers of direct-to-consumer genetic tests to share the data. Thus overall, participants' knowledge was rather low, with M = 2.42 (SD = 1.08, range: 0-4) for knowledge about the use of genetic data, and M = 1.52 (SD = 0.77, range: 0-3) for knowledge about the privacy aspects of genetic data sharing.

4.3 | Bivariate correlations between WTS, psychological variables and sociodemographics

Bivariate correlations were conducted and are presented in Table 3. All the postulated psychological factors from the model were significantly related to participants' WTS, and correlation magnitudes suggest that particularly benefit perception and trust play important parts for WTS. Knowledge about the use of genetic data for research was related to benefit perception, while privacy knowledge was solely related to risk perception. In addition to the psychological variables, a number of sociodemographic and other individual variables were

TABLE 3 Pearson product-moment correlation between WTS and predictive factors (N = 416)

	WTS	Risk perception	Benefit perception	Trust	Knowledge: Use	Knowledge: Privacy
WTS	-					
Risk perception	–.34***	-				
Benefit perception	.48***	–.30***	-			
Trust	.48***	–.44***	.58***	-		
Knowledge: use	.14**	.01	.22**	.06	-	
Knowledge: privacy	–.03	.16**	–.07	–.13**	.29***	-

Note: *P < .05;**P < .01;***P < .001.

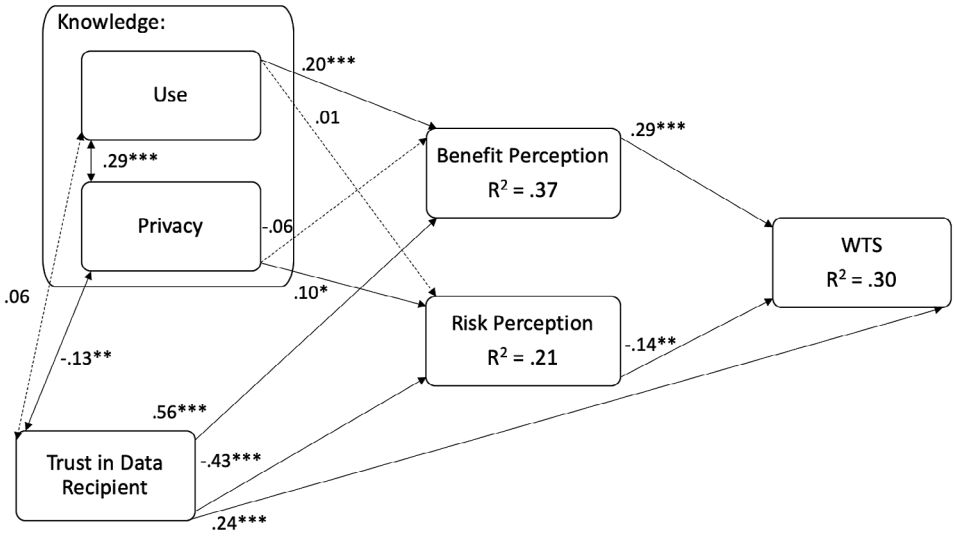

FIGURE 3 Estimated model with standardized regression weights (N = 416, *P < .05, **P < .01, ***P < .001)

tested regarding their relationships with people's WTS. There was no significant relationship for age (r = –.04, P = .441) or perceived health (r = .03, P = .520), but participants with higher digital affinity reported a higher WTS (r = .14, P < .001). There was no gender effect (t[414] = 0.15, P = .884, r = .01); men and women were equally likely to share their genetic data. Furthermore, WTS did not differ depending on the participants' education (low: M = 4.06, SD = 1.99; medium: M = 4.10, SD = 1.96; high: M = 4.09, SD = 1.90; F[2, 413] = 0.01, P = .993, η^2 = .00). However, there was a significant difference in WTS for people with (M. = 4.41, SD = 1.97) and without chronical illness (M = 3.98, SD = 1.91; t(414) = 2.02, P = .044, r = .10.

4.4 | Path analysis

In a final analysis step, the postulated path model was fitted, which exhibited a good fit with the following fit indices: CFI = .99, TLI = .98, and RMSEA = .04. Figure 3 presents the path model. The standardized regression weights suggest a stronger influence of benefit perceptions on people's WTS compared with risk perceptions. Furthermore, trust in the data recipient was directly and indirectly (via perceptions) related to WTS. Finally, knowledge had an impact on people's perceptions in the way that people with a higher degree of knowledge about the use of genetic data expressed higher benefit perceptions and people with a higher degree of knowledge about privacy aspects expressed higher risk perceptions. Overall, 30% of the variance could be explained in WTS by the suggested model.

5 | DISCUSSION

The key findings of this study are as follows: first, benefit perception appears to be the key factor in people's WTS, while risks were less salient, and second, the fact that knowledge was related to people's perceptions. Overall, participants seemed willing to provide their genetic data. This reflects other research that was conducted here in Switzerland regarding the WTS of older Swiss adults and university students.[47,48] Mahlmann et al[47] found in their study that “curiosity” and “for research” were the most frequently stated reasons for undergoing genetic testing. Thus, WTS in this scenario might be higher than in other scenarios, as participants were explicitly reminded that their data would serve science and research. Interestingly, WTS did not differ substantially depending on the type of genetic data that people were asked to share, which suggests that participants approached the subjects with an “all or nothing” approach. This might be related to participants' lack of knowledge regarding the uses and possibilities of different types of genetic data.

Participants who perceived more benefits associated with data sharing were particularly willing to share their data for research. As participants with higher knowledge of the potential use of genetic data for research perceived more benefits, WTS can likely be improved by providing people with relevant information. While it is a promising finding that consumers' general WTS is rather high for research purposes, it might still be important to look closer at people's risk perceptions. Previous research[30,41,43] suggests that consumers have little knowledge about data sharing, privacy and potential risks. Mostly, people are concerned about potentially negative effects if the data are (mis-)used by health insurers or employers, while privacy and confidentiality seem to be abstract and not well-defined constructs.[41,49,50] As is known from research into people's acceptance of innovations and technology, experts and laypeople tend to differ in their risk prioritization,[51] a fact that is explained by both differences in knowledge and expertise, and different uses of the intuitive and heuristic system of judgement and decision-making.[37] In light of previous research[41] and the emerging public discourse and data scandals (eg, Facebook sharing personal data with private company for profit), risk factors should not be disregarded, as people's risk perceptions and their role for WTS might increase. Especially in the sensitive area of health, medical and genetic data, future research should strive to understand people's shifting perceptions and preferences.

In the fast-changing and complex digital world, it is important to enable consumers to make optimal use of the analytical system to judge whether and with whom they want to share which health or genetic data. While the reliance on benefit perception and trust might increase WTS, risks might still emerge for consumers that cannot entirely be tackled by increasing data security and safety. Currently, it appears that due to incomplete and asymmetric information, people are not adequately equipped to judge the involved risks and protect themselves accordingly. This lack of knowledge is compensated for by trust in the acting entity, which might—in some instances—be a faulty strategy for people.[19,40,52] Trust is rooted in people's perceptions that the acting entity has the same intentions and similar values as they do.[53] While public trust in some instances might be quickly lost, it can be generated with potentially misleading information. The perception of similar intentions and values can deliberately, but most importantly also unwittingly, be manipulated and, thus, lead people to trust institutions or entities that do not act in their interest (eg, share their data with third parties). Based on the level of anonymity (ie, anonymous, could be matched with personal data, directly identifiable), the sharing of data might have varying consequences for people. These consequences range from financial and privacy risks due to the sharing of data with third parties to frustration and reduced WTS when the data are not used for the indicated purposes. As ideas, such as "crowdsourced data" are more and more topics of public discourse, it is desirable to enable people to make informed choices regarding their data and weigh personally relevant risks and perceived benefits.

5.1 | Implications for research and practice

In their systematic review of people's concerns about genetic privacy and their WTS, Clayton et al[41] state that too little research looks deeper at the most salient concerns that people might have about sharing their data with research. The present study additionally points to a need for further research into salient and tangible benefits that leverage trust that people put into researchers, despite potential risks that data sharing might pose. Future research could experimentally vary the information provided regarding the involved benefits and risks and draw from experiences in other areas where data sharing is of importance. This way, the most salient concerns and driving factors could be identified. Information provision should particularly stress the improvement of public health and less the advancement of medical research, as the former might be more personally relevant. In addition to information provision, data storage systems should take into account people's perceptions and avoid misunderstandings in decision-making (eg, privacy by design, easily understandable choices for informed decision-making). An easily understandable interface and transparent choices will support informed decision-making and likely increase WTS.[10]

A few limitations of the present study should be addressed at this point. First, the study participants were part of a market research panel and, thus, might not be representative for the population of Swiss residents. However, during recruiting, care was taken to avoid additional selection bias and to ensure a heterogeneous sample in terms of gender and age (ie, neutral invitation and starting page that did not refer to the topic of genetic data sharing, age and gender quotas). Second, self-report WTS was assessed in this study. The Privacy Paradox[50,54] suggests discrepancies in people's stated and actual WTS. It would be of interest to see if the same model (and factors, ie, benefit perception and trust) determines people's actual WTS. For instance, this could be investigated in a study that requires participants to assess health or genetic data and to subsequently ask them to share this data for research. This would allow for comparisons between participants and nonparticipants and test the model suggested in this study. Furthermore, in our measure of WTS, we did not differentiate between participants' willingness-to-generate data (ie, take a genetic test) and their willingness-to-share these data. We asked participants to imagine that they had already collected these data, as we wanted to minimize selection bias. However, this might have forced participants into responding to a question that is irrelevant to them (willingness-to-share genetic data), as they would never take a genetic test. However, the willingness to generate and share data will likely be related, which is an aspect that should be considered in future studies. On a similar note, the scenario presented to the participants was of a hypothetical nature. Despite this, the decisional context of "health data sharing" is not a vague future issue, as there is an active public discourse on this and several existing health data storage systems that allow the sharing of data with medical personnel and researchers.

5.2 | Summary

To sum up, the present study stresses the importance of individual factors, such as salient benefits and trust in data recipient, for people's

WTS and contribute to research. Particularly, people seem to be driven by (mostly) altruistic motives of improving public health and contributing to the diagnosis and treatment of diseases. The results point to the need for more information on the use of genetic data and also to raise awareness for particular privacy issues. This is particularly important in light of the knowledge gap between stakeholders (eg, researchers) and the people potentially sharing their data (eg, patients, participants), with the latter having little knowledge. A heavy reliance on trust in the data recipient might not be a satisfactory strategy for people, as this might be manipulated by the data recipient. Thus, future efforts should focus on finding ways to encourage informed decision-making, without discouraging people from sharing their data for the benefit of public health.

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CONFLICTS OF INTEREST

The authors declare no conflict of interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

1. Yank V, Agarwal S, Loftus P, Asch S, Rehkopf D. Crowdsourced health data: comparability to a US National Survey, 2013–2015. *Am J Public Health*. 2017;107(8):1283-1289.
2. Brabham DC, Ribisl KM, Kirchner TR, Bernhardt JM. Crowdsourcing applications for public health. *Am J Prev Med*. 2014;46(2):179-187.
3. Bastarache L, Hughey JJ, Hebbring S, et al. Phenotype risk scores identify patients with unrecognized Mendelian disease patterns. *Science*. 2018;359(6381):1233.
4. Phillips M. International data-sharing norms: from the OECD to the general data protection regulation (GDPR). *Hum Genet*. 2018;137(8):575-582.
5. Townend D. Conclusion: harmonisation in genomic and health data sharing for research: an impossible dream? *Hum Genet*. 2018;137(8):657-664.
6. Khan A, Capps BJ, Sum MY, Kuswanto CN, Sim K. Informed consent for human genetic and genomic studies: a systematic review. *Clin Genet*. 2014;86(3):199-206.
7. Vayena E, Mastroianni A, Kahn J. Ethical issues in Health Research with novel online sources. *Am J Public Health*. 2012;102(12):2225-2230.
8. Vayena E, Salathé M, Madoff LC, Brownstein JS. Ethical challenges of big data in public health. *PLoS Comput Biol*. 2015;11(2):e1003904.
9. Acquisti A, Brandimarte L, Loewenstein G. Privacy and human behavior in the age of information. *Science*. 2015;347(6221):509-514.
10. Acquisti A, Grossklags J. Privacy and rationality in individual decision making. *IEEE Security Privacy*. 2005;3(1):26-33.
11. Oliver JM, Slashinski MJ, Wang T, Kelly PA, Hilsenbeck SG, McGuire AL. Balancing the risks and benefits of genomic data sharing: genome research participants' perspectives. *Public Health Genomics*. 2012;15(2):106-114.
12. Papoutsi C, Reed JE, Marston C, Lewis R, Majeed A, Bell D. Patient and public views about the security and privacy of electronic health records (EHRs) in the UK: results from a mixed methods study. *BMC Med Inform Decis Mak*. 2015;15:86.
13. Trinidad SB, Fullerton SM, Bares JM, Jarvik GP, Larson EB, Burke W. Genomic research and wide data sharing: views of prospective participants. *Genet Med*. 2010;12(8):486-495.
14. Vayena E, Gourna E, Streuli J, Hafen E, Prainsack B. Experiences of early users of direct-to-consumer genomics in Switzerland: an exploratory study. *Public Health Genomics*. 2012;15(6):352-362.
15. Sanderson SC, Brothers KB, Mercaldo ND, et al. Public attitudes toward consent and data sharing in biobank research: a large multisite experimental survey in the US. *Am J Hum Genet*. 2017;100(3):414-427.
16. Bearth A, Siegrist M. Are risk or benefit perceptions more important for public acceptance of innovative food technologies: a meta-analysis. *Trends Food Sci Technol*. 2016;49:14-23.
17. Siegrist M. Factors influencing public acceptance of innovative food technologies and products. *Trends Food Sci Technol*. 2008;19(11):603-608.
18. Ronteltap A, van Trijp JCM, Renes RJ, Frewer LJ. Consumer acceptance of technology-based food innovations: lessons for the future of nutrigenomics. *Appetite*. 2007;49(1):1-17.
19. Siegrist M, Cvetkovich G, Roth C. Salient value similarity, social trust, and risk/benefit perception. *Risk Anal*. 2000;20(3):353-362.
20. Gupta N, Fischer ARH, Frewer LJ. Socio-psychological determinants of public acceptance of technologies: a review. *Public Underst Sci*. 2012;21(7):782-795.
21. Raue M, Lermer E, Streicher B. *Psychological Perspectives on Risk and Risk Analysis*. Cham, CH: Springer; 2018.
22. Lemke AA, Wolf WA, Hebert-Beirne J, Smith ME. Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics*. 2010;13(6):368-377.
23. Lemke AA, Halverson C, Ross LF. Biobank participation and returning research results: perspectives from a deliberative engagement in south side Chicago. *Am J Med Genet A*. 2012;158A(5):1029-1037.
24. McGuire AL, Hamilton JA, Lunstroth R, McCullough LB, Goldman A. DNA data sharing: research participants' perspectives. *Genet Med*. 2008;10(1):46-53.
25. Shah N, Coathup V, Teare H, et al. Motivations for data sharing-views of research participants from four European countries: a DIRECT study. *Eur J Hum Genet*. 2019;27(5):721-729.
26. Abrams LR, Koehly LM, Hooker GW, Paquin RS, Capella JN, McBride CM. Media exposure and genetic literacy skills to evaluate Angelina Jolie's decision for prophylactic mastectomy. *Public Health Genomics*. 2016;19(5):282-289.
27. Abrams LR, McBride CM, Hooker GW, Cappella JN, Koehly LM. The many facets of genetic literacy: assessing the scalability of multiple measures for broad use in survey research. *PLoS One*. 2015;10(10):e0141532.
28. Boerwinkel DJ, Yarden A, Waarlo AJ. Reaching a consensus on the definition of genetic literacy that is required from a twenty-first-century citizen. *Science Edu*. 2017;26(10):1087-1114.
29. McGuire AL, Fisher R, Cusenza P, et al. Confidentiality, privacy, and security of genetic and genomic test information in electronic health records: points to consider. *Genet Med*. 2008;10(7):495-499.
30. Christofides E, O'Doherty K. Company disclosure and consumer perceptions of the privacy implications of direct-to-consumer genetic testing. *New Genet Soc*. 2016;35(2):101-123.
31. Hansen J, Holm L, Frewer L, Robinson P, Sandøe P. Beyond the knowledge deficit: recent research into lay and expert attitudes to food risks. *Appetite*. 2003;41(2):111-121.
32. Chowdhury PD, Haque CE, Driedger SM. Public versus expert knowledge and perception of climate change-induced heat wave risk: a modified mental model approach. *J Risk Res*. 2011;15(2):149-168.

33. Kraus N, Malmfors T, Slovic P. Intuitive toxicology - expert and lay judgments of chemical risks. *Risk Anal*. 1992;12(2):215-232.
34. Rowe G, Wright G. Differences in expert and lay judgments of risk: myth or reality? *Risk Anal*. 2001;21(2):341-356.
35. Bearth A, Cousin M-E, Siegrist M. "The dose makes the poison": informing consumers about the scientific risk assessment of food additives. *Risk Anal*. 2016;36(1):130-144.
36. Boase N, White M, Gaze W, Redshaw C. Evaluating the mental models approach to developing a risk communication: a scoping review of the evidence. *Risk Anal*. 2017;37(11):2132-2149.
37. Chauvin B. Individual differences in the judgment of risks: sociodemographic characteristics, cultural orientation, and level of expertise. In: Raue M, Lermer E, Streicher B, eds. *Psychological Perspectives on Risk and Risk Analysis*. Cham, CH: Springer; 2018.
38. Acquisti A, Adjerid I, Brandimarte L. Gone in 15 seconds: the limits of privacy transparency and control. *Security Privacy*. 2013;11(4):72-74.
39. Brothers KB, Morrison DR, Clayton EW. Two large-scale surveys on community attitudes toward an opt-out biobank. *Am J Med Genet A*. 2011;155A(12):2982-2990.
40. Earle TC, Siegrist M, Gutscher H. Trust, risk perception and the TCC model of cooperation. In: Earle TC, Siegrist M, Gutscher H, eds. *Trust in Risk Management: Uncertainty and Scepticism in the Public Mind*. London, UK: Earthscan; 2007.
41. Clayton EW, Halverson CM, Sathe NA, Malin BA. A systematic literature review of individuals' perspectives on privacy and genetic information in the United States. *PLoS One*. 2018;13(10):e0204417.
42. Critchley C, Nicol D, Otlowski M, Chalmers D. Public reaction to direct-to-consumer online genetic tests: comparing attitudes, trust and intentions across commercial and conventional providers. *Public Underst Sci*. 2015;24(6):731-750.
43. Haga SB, Barry WT, Mills R, et al. Public knowledge of and attitudes toward genetics and genetic testing. *Genet Test Mol Biomarkers*. 2013;17(4):327-335.
44. *IBM SPSS Statistics for Windows* [computer program]. Version 25. Armonk, NY: IBM Corp; 2017.
45. *Amos [Computer Program]* [computer program]. Version 23. Chicago, IL: IBM SPSS; 2014.
46. Greszki R, Meyer M, Schoen H. The impact of speeding on data quality in nonprobability and freshly recruited probability-based online panels. In: Callegaro M, Baker R, Bethlehem J, Göritz AS, Krosnick JA, Lavrakas PJ, eds. *Online Panel Research: A Data Quality Perspective*. Chichester, UK: John Wiley & Sons Ltd; 2014.
47. Mahlmann L, Rocke C, Brand A, Hafen E, Vayena E. Attitudes towards personal genomics among older Swiss adults: an exploratory study. *Applied Transl Genomics*. 2016;8:9-15.
48. Vayena E, Ineichen C, Stoupka E, Hafen E. Playing a part in research? University students' attitudes to direct-to-consumer genomics. *Public Health Genomics*. 2014;17(3):158-168.
49. Lee SSJ, Borgelt E. Protecting posted genes: social networking and the limits of GINA. *Am J Bioethics*. 2014;14(11):32-44.
50. Kokolakis S. Privacy attitudes and privacy behaviour: a review of current research on the privacy paradox phenomenon. *Comput Secur*. 2017;64:122-134.
51. Siegrist M, Hübner P, Hartmann C. Risk prioritization in the food domain using deliberative and survey methods: differences between experts and laypeople. *Risk Anal*. 2018;38(3):504-524.
52. Siegrist M, Cvetkovich G. Perception of hazards: the role of social trust and knowledge. *Risk Anal*. 2000;20(5):713-720.
53. Siegrist M. Trust and risk perception: a critical review of the literature. *Risk Anal*. 2020; https://doi.org/10.1111/risa.13325.
54. Barth S, de Jong MDT. The privacy paradox – investigating discrepancies between expressed privacy concerns and actual online behavior – a systematic literature review. *Telemat Informat*. 2017;34(7):1038-1058.

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